

55 Impact of patient hematocrit on CF newborn screening results

H. Wilde², M. Montgomery³, L. Baskin¹, D. Gray¹, M. Lyon^{1,2}. ¹Calgary Lab Services, Calgary, AB, Canada; ²Univ of Calgary, Calgary, AB, Canada; ³Alberta Children's Hospital, Calgary, AB, Canada

Aim: To evaluate the effect of patient hematocrit on the measurement of pancreatitis associated protein (PAP) from a dried blood spot specimen.

Methods: (1) All neonatal (<28 days old) hematocrit results were tabulated for 1 month (clinical lab database). (2) Newborns were retrospectively identified if dried blood spots were obtained for newborn CF screening on more than one occasion over a 1 year time frame. For each specimen, gestational age and post-natal ages were collected. (3) A whole blood sample was spiked with PAP (0.1 ng/ml) and the cell pack volume adjusted to achieve three aliquots containing hematocrits of 0.18, 0.40 and 0.59. These were then applied to Whatman 903 newborn screening cards. The influence of hematocrit on the measurement of PAP (Dynabio PAP ELISA, Marseille, France) was investigated.

Results: Hematocrit levels (mean±SD) for 0–6, 7–13, 14–20 and 21–27 days were 0.485±0.085, 0.413±0.079, 0.364±0.071 and 0.336±0.06, respectively (N=608 for all neonates <28 days old). A total of 16,074 neonates were screened for CF over 1 year with 205/16,074 (1.3%) neonates having more than one dried blood spot collected. The mean age difference between sample collections was 19 days for babies 25–29 weeks gestation to 11 days for babies 30–37 weeks gestation. PAP concentrations detected were inversely affected by hematocrit with the lowest results obtained from the specimen with the highest hematocrit (0.59).

Conclusions: (1) Hematocrit levels decrease significantly during the first four weeks of life. (2) Repeat newborn sampling is rarely conducted within 7 days, therefore hematocrit changes may need to be considered. (3) Hematocrit affects the measurement of PAP from dried blood spots.

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56 Parental experience of the CF Service in the first year after diagnosis

M. Musgrave¹, R. Iles¹, M. Polichroniadis¹, D. McShane¹. ¹Respiratory Paediatrics, Addenbrookes' NHS Trust, Cambridge, United Kingdom

Neonatal screening for Cystic Fibrosis (CF) enables children to be seen by specialist CF Teams at the earliest opportunity, often when the child is asymptomatic. The time of diagnosis is arguably one of the most important and distressing for a CF family, with diagnosis being likened to bereavement. The early stage management of CF is often focused on education and supporting the family.

We have developed a service over many years to aid the families through diagnosis, however little is actually known of the parents' experience. In order to understand this area better and improve our service, an audit was commissioned for parents of children diagnosed with CF between 2004–2006.

The audit questionnaire focused on initial diagnosis, the roles and attributes of the CF team, and the quality and content of information. A sample of 19 was available for the study, a good response of 13/19 (68%) was achieved.

The feedback given was that the approach to diagnosis was achieved well at 62% (8/13). 100% (13/13) thought the gradual introduction of the team worked well. Improvements to contact details were suggested. 85% (11/13) had a high level of confidence in the team through accessibility of staff for clinic or home visits and direct communication to all team members. 69% (9/13) felt the Team's communication skills were very effective and 69% (9/13) thought the information that was provided by the team was very consistent.

We have found this audit beneficial in re-designing our service. Suggested changes were implemented for example; cough swab results are given whether positive or negative.